Assisted Living: Promising Policies & Practices to Improve Care and Quality of Life

Presented by Richard Mollot & Sean Whang, Long Term Care Community Coalition

www.nursinghome411.org
About the Long Term Care Community Coalition

- **LTCCC**: Nonprofit organization dedicated to improving care & quality of life for the elderly & adult disabled in long term care (LTC).

- **Our focus**: People who live in nursing homes & assisted living.

- **What we do**:  
  - Policy analysis and systems advocacy in NYS & nationally;
  - Education of consumers and families, LTC Ombudsmen and other stakeholders;
  - Home of the local LTC Ombudsman Program for the Hudson Valley, New York.


- **Sean Whang**: Policy fellow. Graduate of Columbia University Mailman School of Public Health.
What Will We Be Talking About TODAY?

**BACKGROUND**
- What is assisted living and how does it differ from nursing homes?
- Strengths and weaknesses of the assisted living model.

**LTCCC’S ASSISTED LIVING REPORT**
- Identifying promising policies & practices to improve care, safety, and dignity.
- Recommendations for prospective residents, facility operators, and policymakers.
- Information on how each state “measures up” in respect to the various polices.

**NEW ASSISTED LIVING FACT SHEETS**
- Each fact sheet addresses an issue relevant to assisted living consumers, from dementia care to staff training to public information on a facility’s ownership or inspection results.
BACKGROUND:
The promise of assisted living...
...and the reality.
The **Promise** of Assisted Living

- Choice and control
- Independence
- Continuing to participate in the outside community
- Services that minimize the need to move
The Reality of Assisted Living
Residential LTC in the USA

**Nursing homes:**
- Most LTC paid for by Medicaid; most rehab paid for by Medicare
- Resident protections under the federal Nursing Home Reform Law (OBRA ‘87) and state regulations, which can augment the Reform Law

**Assisted living:**
- Mostly private pay
- Small but growing Medicaid population
- No federal safety standards
- State standards tend to be very low, and less focused on ensuring health and safety

“Medical Model” vs. “Social Model”
But what happens when the social model takes in residents with the same needs as the medical model?
Recognize that the typical nursing home is a poor place to live and get care.

Assisted living facilities (ALFs) provides an attractive alternative for those who need or desire residential care.

Longstanding concerns about quality of care, safety, oversight, whether assisted living is fulfilling its promises in respect to quality of life.

How to balance:
  - Social model vs. people with clinical and other care needs
  - Private pay vs. access for individuals with lower income (Medicaid)
  - ALF “flexibility” vs. residents’ rights vs. residents’ desires.

For example: ALF that does not want to – or cannot – have residents who are wheelchair bound. Isn’t this discriminatory against those residents? What about residents who do not want to be in an ALF with residents who are wheelchair bound?
GAO Report

The U.S. Government Accountability Office (GAO) is an independent, nonpartisan agency that works for Congress. Often called the "congressional watchdog," GAO examines how taxpayer dollars are spent and provides Congress and federal agencies with objective, reliable information to help the government save money and work more efficiently.


Forty eight states participated in the survey, which covered the year 2014 and focuses specifically on assisted living services provided to Medicaid beneficiaries. GAO-18-179 (Jan. 2018). Available at www.gao.gov/.

Washington, DC was included in the survey while three states, Kentucky, Louisiana, and West Virginia, were not included because they reported that they did not pay for assisted living services.
GAO Report: Key Findings

- Americans spend more than $10 billion per year in federal and state Medicaid funding to provide access to assisted living for 330,000 people.

- Nationally, the average spending per beneficiary on assisted living services in the 48 states in 2014 was about $30,000.

- Though state Medicaid agencies retain “ultimate administrative authority and responsibility” over the quality, safety, and integrity of Medicaid assisted living services, GAO found that:
  - Fewer than half the states surveyed (22 of the 48) were able to provide any information on abuse, neglect, exploitation, and death of residents (so-called “Critical Incidents”).
  - Those 22 states alone reported nearly 23,000 Critical Incidents in 2014.
Delegation of important responsibilities from the state agencies to other agencies is widespread.

Despite fundamental responsibility to oversee quality and safety, GAO identified significant failures among state agencies to even review Critical Incident reports, exclusion lists, reports of abuse, and LTC Ombudsman findings, provided by those agencies.

The 48 state Medicaid agencies varied in:

1. their ability to report the number of Critical Incidents in their states;
2. how they defined what a Critical Incident is, and
3. the extent to which they made information on Critical Incidents readily available to the public.
Because GAO only looked at Medicaid assisted living – a small minority of assisted living consumers – and only received information from 22 states – the actual number of critical incidents is likely many times greater than 23,000 per year.

State oversight has failed assisted living residents and the taxpayers who help pay for their care.

Need for Stronger Standards & Transparency About Quality & Services
Questions:

- We know that there are good ALFs and bad ALFs – what are the good ones doing?

- We know that, though state regulations tend to be weak, there are some good standards out there – what are they?

- Following the GAO report, what are states doing to protect residents?

Goal: To identify good policies and practices for...

- State and federal policymakers
- The assisted living industry
- Consumers
What did we focus on?

- Staffing Requirements: Registered Nurses
- Staffing Requirements: Administrators
- Staffing Requirements: Staff Ratios
- Staffing Requirements: Recreational Activities Directors
- Staff Training Requirements
- Dementia Care
- Oversight & Quality Assurance
- Resident & Family Councils
- Abuse & Neglect
- Transfer & Discharge
- Consumer Information (Disclosures)
- Public Information: Survey Reports & Complaint Investigations
A few findings...

- Only 10 states have some kind of staff ratio
- 16 states do not have a dementia care staff proficiency requirement (training and/or licensure)
- 17 states do not have a requirement for an RN on staff
- Half the states require less than annual inspections...
Dementia Care

Introduction
About 70 percent of assisted living residents live with Alzheimer’s Disease or some form of dementia.12 Sadly, and all too often, policies and practices meant to address the needs of individuals suffering from dementia are lacking in these communities. A recent study found that, while two-thirds of sampled assisted living facility (ALF) residents had dementia, staff only identified 40 percent of these residents.13

To better address the needs of this large and growing population in assisted living, it is essential that ALFs that accept and/or retain individuals with dementia, ensure that their staff have appropriate training, that physical environments are safe, and that social and other programs are tailored to meet the psycho-social needs of these individuals.

Key Best Practices

1. Provide dementia safe and friendly physical environment
   - Ensure that areas of the facility to which residents with dementia (or other cognitive impairment) have access have secured entrances and exit ways, appropriate pathways, and lighting suitable for individuals with dementia.
   - Room doors and interiors should be individualized to help residents recognize their own rooms.
   - Room furnishings should be personalized, to the extent possible, to provide a familiar and comfortable environment.
   - ALFs that accept and/or retain individuals with dementia should be expected to provide “aging in place” within their facilities for residents, by enabling residents with dementia to safely remain in their apartment or room. In particular, appropriate services should be brought to the resident in his/her home, rather than forcing residents with dementia to undergo a potentially confusing and stressful move to a special floor or unit.

2. Staffing
   - ALFs that provide care to residents with dementia should provide at least three hours of direct care staff time per resident per day.
   - Staff should be present in the facility and awake, with the ability to monitor residents, 24-hours per day.
   - A registered nurse (RN) must be employed and in the building at least one shift a day, 7-days a week, with access to an RN available at other times.

3. Staff training
   - Administrators and direct care workers (DCWs) should undergo 12 and four hours of initial training in dementia care, respectively.

Administrators and DCWs, as well as other staff in the facility that are in contact with residents with dementia (including laundry, food service, social work, and janitorial staff) should undertake a minimum of four hours of dementia care training annually.

Training should include: understanding cognitive impairment, behavioral and psychological symptoms of dementia, communication with individuals who have dementia, identifying and addressing incidents of abuse and neglect towards residents with dementia, and non-pharmacological approaches and other standards of dementia care.

4. Assess residents’ cognitive condition
   - Ensure that each resident with a clinical diagnosis of dementia or other cognitive impairments is properly treated by specialized DCWs.

5. Public disclosures
   - All marketing materials and residency agreements should clearly articulate the scope of dementia care services provided and designate any services for which an additional fee might be incurred.

6. Individualized care plans
   - Individualized care plans should also be made more explicit to ensure customized care for each resident with dementia.
   - Include distinctions between different levels of dementia to understand how to provide the best quality of care for residents with different forms of dementia.

Selected State Policies

Georgia:
In addition to all other requirements... where an assisted living community holds itself out as providing additional or specialized care to persons with probable diagnoses of Alzheimer’s Disease or other dementia or charges rates in excess of that charged other residents because of cognitive deficits which may place the residents at risk of eloping, the assisted living community must meet the following requirements:

(a) Written Description. The assisted living community must include in its licensed residential care profile an accurate written description of the special care unit that includes the following:
   1. a statement of philosophy and mission;
   2. how the services and activities of the special care unit are different from those provided in the rest of the assisted living community;
   3. staffing including job titles of staff who work in the unit, staff training and continuing education requirements;
   4. admission procedures, including screening criteria;

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13 Id.
Following is a snapshot of the chart of state policies and requirements. The full chart is available at [https://nursinghome411.org/assisted-living-state-requirements-chart/](https://nursinghome411.org/assisted-living-state-requirements-chart/).

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<th>Website</th>
<th>Frequency of Inspections</th>
<th>Financial Penalties</th>
<th>Staffing Hours/Ratio</th>
<th>Percent Not Receiving Antipsychotic Drugs</th>
<th>Aide Training or Certification Reqmt</th>
<th>Dementia Care Staff Proficiency Reqmt (training and/or licensure)</th>
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Assisted Living Fact Sheets
LONG TERM CARE
COMMUNITY COALITION
WWW.NURSINGHOME411.ORG

Assisted Living Fact Sheet:
Detecting and Addressing Abuse and Neglect

The U.S. Government Accountability Office’s (GAO) 2018 report on assisted living indicates that tens of thousands of residents experience “critical incidents” – including abuse, neglect, exploitation, and death – in their assisted living facilities (ALFs) every year. The GAO also found that more than half of the states do not even have a system in place for tracking cases of critical incidents. This indicates that the number of critical incidents involving residents is actually much higher than what the GAO found.

Unfortunately, the GAO report does not specify which states track critical incidents, making it difficult for seniors and their families, and their political representatives, to know what is going on in the ALFs in their states and communities. To assist both consumers and policymakers, LTCCC assessed state activities in respect to publication of ALF survey (inspection) results and remedies imposed when violations are found.

The following page has maps indicating each state’s policies for reporting ALF survey results and remedies. Below are some of the key recommendations for implementing abuse and neglect standards from our report, Assisted Living: Promising Policies and Practices for Improving Resident Health, Quality of Life, and Safety.

Recommended Practices & Policies to Address Abuse and Neglect

- All ALF employees should undertake training upon employment that includes coverage of identifying, preventing, and reporting abuse, neglect, and other critical incidents.
- Any ALF employee who has contact with residents, including care staff, recreational and social work, food service, and housekeeping staff, should undergo annual training on identifying, preventing, and reporting abuse, neglect, and other critical incidents.
- States should have a consistent definition of what comprises a “critical incident” and be expected to monitor and review such incidents on an ongoing basis.
- State surveyors should undergo annual training focused on supporting their ability to identify and evaluate potential incidents of abuse, neglect, exploitation, and other critical incidents.
- States should publish information on substantiated critical incidents on their websites on a quarterly basis, including: the name and location of the ALF; a description of the critical incidents; the remedy imposed (if any); and the ALF’s plan of correction.

NOTE: This is a partial list. To see all of our recommendations, please see LTCCC’s report on the Assisted Living page of our website, www.nursinghome411.org.

Maps of State Requirements

- 28 states and the District of Columbia do not publish remedies in response to critical incidents online. 22 states publish remedies in response to critical incidents online.

Further Reading

2. LTCCC’s Assisted Living State Requirements Chart offers a comparative look at state requirements, including those involving abuse and neglect. See https://nursinghome411.org/assisted-living-state-requirements-chart/

Note: This document is the work of LTCCC. It does not necessarily reflect the views of the Department of Health, nor has the Department verified the accuracy of its content.

For additional information and resources, please visit www.nursinghome411.org.
Fact Sheet: Staff Training Requirements

Assisted Living Fact Sheet: Staff Training Requirements

Staff training, knowledge, and skills are essential to good assisted living resident care. If staff members are not properly trained to meet residents’ needs, residents will likely have a greater risk of experiencing poor outcomes and harm (such as that resulting from abuse or neglect), and even death.

Unfortunately, there are no federal standards for staff training or requirements that facilities employ professional staff. A number of states require assisted living facility (ALF) staff to undergo training during their initial orientation and/or thereafter. However, these requirements vary and, from a consumer perspective, tend to be very low. This is due to the assisted living industry marketing itself for years as a “social” rather than “medical” model. However, with increasing numbers of residents living in assisted living with dementia and other significant needs, the ALF population is increasingly similar to those living in nursing homes, but without the staff licensure, training, or other critical requirements.

LTCCC has conducted a nationwide analysis of best practices in assisted living and has published a report with recommendations for improving resident health, safety, and well-being. The following are some key recommendations for implementing training standards in assisted living from our report, Assisted Living: Promising Policies and Practices for Improving Resident Health, Quality of Life, and Safety. On the following page is a map indicating what states do – and do not – have training requirements.

Recommendations

- ALFs should require that training be completed within the first 30 days of hire.
- ALFs should ensure that training equips staff with skills in and knowledge of a range of subject areas critical to resident safety and well-being, including: emergency preparedness, Alzheimer’s and other dementia, residents’ rights, detecting abuse and neglect, communication skills, and (as appropriate) assisting with medication.
- ALFs should categorize training requirements depending on staff type (i.e., administrator, staff working with residents who have dementia, staff assisted residents with activities of daily living [ADLs]).
- ALF staff that are in contact with residents and/or their records should also receive appropriate training in dignity, autonomy, and privacy.
- ALFs should prohibit unsupervised resident contact prior to the completion of training.
- ALFs should conduct training assessments to ensure that staff members recall what they learned during training and are implementing this knowledge appropriately while providing care.

**NOTE:** This is a partial list. To see all of our recommendations, please see the [report](#).

Map of State Requirements

- 47 states and the District of Columbia require direct care workers (DCWs) to undergo and complete training.
- 3 states do not have training requirements.

**NOTE:** Training requirements described in the map below reflect those specific to the initial orientation. Training requirements for annual or continuous education may differ.

Further Reading

2. LTCCC’s Assisted Living State Requirements Chart offers a comparative look at state requirements, including training standards. See [https://nursinghome411.org/assisted-living-state-requirements-chart/](https://nursinghome411.org/assisted-living-state-requirements-chart/).

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For additional information and resources, please visit [www.nursinghome411.org](http://www.nursinghome411.org).
Fact Sheet: Dementia Care

LONG TERM CARE COMMUNITY COALITION
WWW.NURSINGHOME411.ORG

Assisted Living Fact Sheet: Dementia Care

About 70 percent of assisted living residents live with Alzheimer’s Disease or some form of dementia. While nursing homes have federal requirements related to dementia care and staff proficiency, there are no federal safety standards for assisted living. As a result, meaningful policies and practices to address the needs of individuals suffering from dementia are, too often, lacking. In fact, a recent study found that, while two-thirds of sampled assisted living facility (ALF) residents had dementia, staff only identified 40 percent of these residents.

To better address the needs of this large and growing population in assisted living, it is essential that ALFs that accept and/or retain individuals with dementia ensure that their staff have appropriate training, that physical environments are safe, and that social and other programs are tailored to meet the psycho-social needs of these individuals.

LTCCC has conducted a nationwide analysis of best practices in assisted living and has published a report with recommendations for improving resident health, safety, and well-being. The following are some key recommendations for assisted living dementia care and safety from our report, Assisted Living: Promising Policies and Practices for Improving Resident Health, Quality of Life, and Safety. Following the recommendations is a map charting which states have dementia care standards for their ALFs.

Recommendations

1. Provide dementia safe and friendly physical environment
   - Ensure that areas of the facility to which residents with dementia (or other cognitive impairment) have access have secured entrances and exit ways, appropriate pathways, and lighting suitable for individuals with dementia.
   - Room doors and interiors should be individualized to help residents recognize their own rooms.
   - Room furnishings should be personalized, to the extent possible, to provide a familiar and comfortable environment.
   - ALFs that accept and/or retain individuals with dementia should be expected to provide “aging-in-place” within their facilities for residents, by enabling residents with dementia to safely remain in their apartment or room. In particular, appropriate services should be brought to the resident in his/her home, rather than forcing residents with dementia to undergo a potentially confusing and stressful move to a special floor or unit.

2. Staffing
   - ACFs that provide care to residents with dementia should provide at least three hours of direct care staff time per resident per day.
   - Staff should be present in the facility and awake, with the ability to monitor residents, 24-hours per day.
   - A registered nurse (RN) must be employed and in the building at least one shift a day, 7-days a week, with access to an RN available at all other times.

3. Staff training
   - Administrators and direct care workers (DCWs) should undergo, respectively, a minimum of 12 and four hours of initial training (within 30 days of employment) in dementia care.
   - DCWs should undertake a minimum of eight hours of in-service training on dementia care annually.
   - Administrators and other staff in the facility that are in contact with residents with dementia (including laundry, food service, social work, and janitorial staff) should undertake a minimum of four hours of dementia care training annually.
   - Training should include: understanding cognitive impairment, behavioral and psychological symptoms of dementia, communication with individuals who have dementia, identifying and addressing incidents of abuse and neglect towards residents with dementia, and non-pharmacological approaches and other standards of dementia care.

4. Public disclosures
   - All marketing materials and residency agreements should clearly articulate the scope of dementia care services provided, the licensure or certification of those providing these services, and designate any services for which an additional fee might be incurred.

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Fact Sheet: Dementia Care

Map of State Requirements

- 38 states have regulations on providing care for residents with dementia. 12 states and the District of Columbia do not have any regulation listed. Note: The type of training (i.e., initial or annual), content, and hours required differ between states.
- States may specifically require that the direct care workers (DCWs) who would provide services to residents with dementia have a license.

Further Reading

2. A corresponding Excel document compares the states by their regulation policies. See https://nursinghome411.org/assisted-living-state-requirements-chart/.

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For additional information and resources, please visit www.nursinghome411.org.
Make Your Voice Heard!
Tell Your Story About Nursing Home or Assisted Living Care

A few background questions.

Thank you for taking the time to tell your story. Hearing from you helps us to provide a strong voice for better care and life with dignity for residents. Please note that we will never divulge any resident’s name, or the name or location of a facility, unless you give us specific permission to do so.

* 1. Are you a:
   - [ ] Resident
   - [ ] Staff Person
   - [ ] Family Member
   - [ ] Ombudsman
   - [ ] Other (please specify)

* 2. Type of facility.
   - [ ] Nursing Home
   - [ ] Assisted Living/Adult Home
   - [ ] Other (please specify)

* 3. Is the experience you are writing about positive or negative?
   - [ ] Positive
   - [ ] Negative

* 4. Did the situation involve abuse, neglect, or other problem? Please select all that apply:
   - [ ] Neglect
   - [ ] Unwanted Discharge From the Facility
   - [ ] Medication
   - [ ] Emotional Abuse
   - [ ] Food or Dining Issue
   - [ ] Communication Problem
   - [ ] Physical Abuse
   - [ ] Sexual Abuse
   - [ ] Theft or Loss
   - [ ] Other (please specify)

5. Did the situation raise concerns about the care the resident was receiving?
   - [ ] Yes
   - [ ] No

6. Did the situation raise concerns about the safety of the resident?
   - [ ] Yes
   - [ ] No

Visit [www.nursinghome411.org](http://www.nursinghome411.org) to fill out or download copies of the form.
Tell Your Story

Tell Your Story About Nursing Home or Assisted Living Care

Thank you for taking the time to tell your story! You can fill out the form below, or download a copy of the "Tell Your Story Form" by clicking on the button to the right. Please share this with others in your home and community by sharing the link to this page or copies of the form.

Tell Your Story About Nursing Home or Assisted Living Care

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3. Is the experience you are writing about positive or negative?

Share This Story, Choose Your Platform!

Computer Screenshot

iPhone Screenshot
“Nothing will happen unless legislators hear from their constituents that this is important.”
Conclusion
Visit

[www.nursinghome411.org](http://www.nursinghome411.org)

for...

- The report
- Chart of state assisted living requirements
- Fact sheets

If you would like to sign-up for alerts on these or other LTC issues, please email [info@ltccc.org](mailto:info@ltccc.org).
Next Program: February 19 at 1pm.

Topic:
Advocacy Issues to Improve Care for Residents with Dementia
Thank You For Joining Us Today!

Email info@ltccc.org or call 212-385-0355 for...

- Invites to future programs,
- News and alerts on important care issues.

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For LTC Ombudsmen in NY State
If you would like us to let your supervisor know that you attended this training program, please take the quick survey at: www.surveymonkey.com/r/ltccc-ltcop1.

For Family Members in NY State
connect with the Alliance of NY Family Councils at www.anyfc.org (or email info@anyfc.org).
Questions?  Comments?

Presentation materials and the webinar recording will be posted on www.nursinghome411.org after each program for future reference.